

infused with the principles of palliative care, and our medical leaders equally respect our bright technological future and the tenets of compassion and prevention which underlie our traditional physician's role.

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LESSONS FROM A SYMPOSIUM ON PALLIATIVE MEDICINE HELD IN THE COLLEGE ON 8TH MARCH 1995*

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The most effective intervention to improve the provision of palliative care would be to employ effectively the knowledge already available. This symposium furthered that goal by not only expounding and exploring important facets of our knowledge of the subject, but also examining the scope for, and obstacles to, disseminating that knowledge to all health professionals and facilitating effective palliative care for all patients.

Palliative medicine services

Palliative care is that of a patient with active progressive and far advanced disease with a limited prognosis for whom the focus of care is the quality of life (rather than quality of death). Patients die; the recognition of this as a natural process is central to the ethics and practice of palliative medicine. All health professionals should acknowledge this fact.

It is important to separate specialist palliative care services from palliative techniques (e.g. ostomies, stenting, orthopaedic procedures, etc.) which are provided by appropriate specialists from the palliative approach (basic caring) which is within the scope of all.

Palliative care services may take several forms: a hospital support team, a ward in a general hospital, a hospice within a general hospital complex, or a freestanding hospice. Each has its own problems. One of the best ways to provide palliative care is to employ an effective hospital-based palliative care support team. This provides an interdisciplinary advisory and supportive service to patients within a general or specialist hospital without having overall responsibility for patients or beds. Although the number of such teams has dramatically increased in the UK the vast majority are unidisciplinary (usually nurses) and are therefore far less effective.

The proportion of people dying at home is currently dropping by 1 per cent per year but patients still spend 90 per cent of the last year of life at home and 90 per cent of symptoms start at home. Home care teams are therefore an essential component of the palliative service. They work by integrating and bridging gaps between the primary care team, community resources and the hospital. They have had no effect on the social trend towards dying in institutions but do enable patients to remain at home longer.

Everyone has the right to receive good palliative care and all professionals have a duty to provide it. The aims for the provision of care are: palliative care for all; appropriate palliative procedures available and accessible to everyone; and specialist services for those few who need them.

*A list of speakers and the titles of their papers presented at this symposium is recorded in *Proceedings*, Vol. 25, p. 354.

The politics of care

In the UK the provision of specialist palliative care involves integrating the views of purchasers, providers, and patients. Determining and addressing the needs of patients, however, is fraught with problems. Most attempts have involved poor surrogate measures; most patients' needs are financial and social rather than medical. The views of purchasers and providers, therefore, largely determine the provision of service.

The main problems involved in contracting are those of definition, measurement, and cost containment. Both sides need to clarify their definition of palliative care, as opposed to the palliative approach, and to agree on clinical criteria. There is increasing pressure to widen these to include all dying patients, and at an earlier stage in their illness. Measuring both quality of care and outcome (mortality rates seem rather inappropriate) are difficult and are made more so by primitive data collection.

At present there is a mixed economy of both providers (NHS units, charitable hospices, etc.) and purchasers (numerous trusts for each palliative care team). Purchasers lack the expertise they need to compare services or to contract for an integration of different services; often only the providers have expert knowledge of what services are needed. Charitable finance often starts new services and then the purchaser is expected to continue to fund them. Lack of knowledge of long term funding is a significant problem in both developing and planning services. One way to help would be to develop purchasing protocols designed to meet agreed clinical guidelines and to buy complete packages of care. A data collection system is currently being developed for this purpose. Future political developments may include primary care led purchasing with the attendant problems of low purchaser expertise, variable, small numbers of patients and the temptation to buy only the cheap parts of the service. The European Association of Palliative Care report recommending integration of palliative care and cancer services, if implemented, will lead to an increase in demand for palliative medicine specialists.

As a specialty, palliative care is vulnerable to public pressure it often leads to the introduction of relatively expensive small in-patient units. These are prone to the danger of domination by a single, strong, personality. Palliative medicine has many strengths: strong popular support, a clear focus, and highly qualified staff working in a self-contained environment where it is easy to maintain standards. Its institutions face the dangers of elitism and isolationism. The extension of palliative care to non-malignant conditions and the expansion of the specialty as an educational resource are major challenges for the future. There is a powerful lobby in support of state funding.

The interface between palliative medicine and other hospital services

Interaction between palliative medicine and other acute hospital services has never been smooth and indeed the origins of the specialty can be seen as a perceived defect in the practice of oncology.

The need for palliative medicine is not a 20th century phenomenon; acute hospitals have never focused on holistic whole-person care and palliative care in them remains poor. Recent papers from both sides of the Atlantic point to deficiencies in even supposed centres of excellence. This suggests that the influence of the specialty on hospital practice is still peripheral at best.

Should acute hospitals be involved in palliative care? There may be little incentive. In the USA, insurance payments relate to diseases and procedures; there is no payment code for dying. In an environment which is so competitive that doctors find it difficult to support each other it is difficult to set up a program to ensure quality care for patients.

There are four main areas where it is important to consider the role of palliative medicine: ethics, patient service, education, and research.

Relieving suffering

This is the basic underlying tenet of the practice of medicine. At present health services focus on an efficiency based management model where the bottom line is monetary savings based on, usually, arbitrary budgets. At the same time most successful large companies are moving away from this bargain basement approach towards an ethics based model. Applying this to health care would require fundamental changes with redistribution of resources away from attempted cure to appropriate care.

In order to achieve good symptom control some dying patients will need access to the advanced diagnostic facilities of an acute hospital. The worst symptom control is amongst the poorest of people and these people are more likely to die in hospital. Although there is a tendency to believe that home is always best this is not so; furthermore, no study has fully assessed the cost of home care versus hospital care in this context.

Early control of symptoms. Pain control, if not achieved early, becomes more difficult because of changes in CNS stimulation. Psycho-social problems, if not addressed early become more intractable. Early and accurate diagnosis of opiate induced confusion, particularly in elderly patients with renal impairment can be addressed by changing the opiate used, and reduces the incidence of this problem from 26 to 10 per cent.

This and other important information presently lies in a hospice cocoon and if it is to reach a wider audience it has to be taught. Good education needs good exemplars and since students and junior doctors still spend most of their training in hospitals palliative medicine needs to be strongly and well represented to them.

The major advances in cancer management in the last fifteen years have been in pain relief, adjuvant drug treatment, control of nausea and vomiting, bone marrow transplantation, and in quality of life research. Three out of these five are palliative care issues. Research in these areas has been limited by logistic, academic, and developmental factors but, increasingly, policy makers call for evidence-based decision making. Palliative care specialists need to be at the forefront of this research effort. All patients should have the right to employ their suffering to benefit themselves or future patients.

Decision making in palliative medicine

Nothing would have greater impact on the quality of palliative care than to use the knowledge we already have. Palliative care presents doctors with a vast number of interconnecting problems making it often very difficult to make appropriate decisions. Palliative care doctors do not work with certainty and trying to impose it will result in decisional paralysis. Most decisions are based on a combination of intuition, experience and evidence. Using intuition, or experience by themselves, however, leads to dead ends where no further decisions

are possible. Using evidence as a basis for our decisions gives us the ability to regularly reassess as new information emerges. In order to make appropriate decisions we need, in addition, a thorough knowledge of pathophysiology, access to good quality evidence and continual updating of the information and of the education of the carers.

Analysis-based decisions allow us, by calculating the probability of an event and the efficacy of a strategy, to decide on the most appropriate way forward. Flow diagrams employing all these factors are a useful way to further clarify our decision making processes. These are not prescriptive but should be regarded as a path through the fog of uncertainty.

The family as the focus of care

For care to be effective it must address the needs of the whole family. It is unhelpful to deal with just the patient, or just with the relatives of that patient. How a family copes with the death of one of its members reflects how it has managed to deal with previous problems. In particular families will handle difficult situations better if the members work as a cohesive unit, have a large repertoire of coping mechanisms, have outside support, and have previous experience of successfully managing stress. Coexisting stress and poor communication can compound difficulties. Enabling family members to communicate better can therefore help them to cope better.

Patients and relatives may have particular problems such as with loss of control resulting from changing roles. A spouse who has always driven the car may no longer be able to do so. This may result in anger, wrongly directed at the partner. By redirecting that anger towards its source, the threat of impending death, we can help families to work together.

Relatives of a dying patient have certain needs. They need to be with the patient and may need to be helpful, although they may need guidance with this. They need information about the patient's condition to be assured of the patient's comfort and need to know when death is approaching. They need acceptance and support and to be able to ventilate emotions.

Throughout the dying process the overall aim is to give the family control. This may need to be removed temporarily at times of crisis, but always with the intention of handing it back.

Global perspectives

Worldwide every year 9 million people develop cancer; by 2015 the figure will be 15 million. For most countries in the developing world modern curative treatments for cancer are prohibitively expensive. Eighty per cent of cancer in developing countries is incurable; most patients do not even present to medical services.

When you have a hammer everything looks like a nail. In Britain and North America many patients with inoperable tumours are still offered curative treatment. In black Africa there are fewer than 100 full-time cancer specialists for 300 million people. In Indonesia 33,000 cancer patients are seen every year out of an estimated 240,000 cases. In India there are ten comprehensive cancer treatment centres providing full oncology services only accessible to 10 per cent of the population. If our aim is sometimes to cure, often to relieve and always to comfort, society fails if it does not address this problem.

By 1994 112 out of 189 World Health Organisation states had committed themselves to a National Cancer Control Programme. The three main aims are primary prevention, early diagnosis, and adequate palliative care (particularly pain relief). The programme is enforced using a combination of rational policies, education, and the provision of appropriate drugs. Policies are important, but to work they should be valid, acceptable and maintainable. They also need to achieve maximum coverage. Pain control can be achieved in 70-90 per cent of cases. In India it is calculated 16,000 patients obtain adequate pain relief, yet 450,000 patients are left in moderate to severe pain.

There are still 51 countries where there is no legally available morphine or codeine. WHO aims to increase global use of opiates and seems to be successful in this; global consumption has increased from two to twelve tonnes per year. Despite this, even in Europe, there remains a thirty-fold difference in consumption of opiates between Denmark and Italy.

In the field of education every country needs to work out its own policies; policies that are applicable to the psychobehavioural modalities of the country. Where in Europe emphasis is placed on individual rights and uniqueness and independence. Africa focuses on group identity, co-operation, and interdependence. The ethos of the western world is survival of the fittest rather than survival of the tribe. In the context of this paper, in many cultures the best way forward is to empower the family, telling them what they are able to do for their relative and how they can do it.

The future of palliative care is not purely medical, and has managerial, financial, political, and ethical implications. Changes in individual and societal attitudes and habits will have far greater impact than purely technical, medical advances and the efforts of professional carers.